A Vision for Minority Health and Health Disparities Research

Eliseo J. Pérez-Stable, M.D.

Director, National Institute on Minority Health and Health Disparities

eliseo.perez-stable@nih.gov

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NIMHD History

1990

2000

2010

2014

2015

2017



Established as an Office under the NIH Director through DHHS Secretary Louis W. Sullivan, M.D. in 1990 Transitioned to a Center through legislation championed by Representative Louis Stokes (D-OH) in 2000 Patient
Protection and
Affordable Care
Act contained
language
championed by
Senator Ben
Cardin (D-MD)
to transition to
an Institute in

John Ruffin, Ph.D. led all the entities until his retirement in March 2014; Yvonne T. Maddox, Ph.D. became Acting Director Eliseo J. Pérez-Stable, M.D., started September 1, 2015

FY 2017 budget is \$289 million





Minority Health Definition

- Minority Health Research focuses on health determinants that lead to specific outcomes within a minority group and in comparison to others
- Race and ethnic minorities share a social disadvantage and/or are subject to discrimination as a common theme





OMB Race/Ethnic Classification

- African American or Black
- Asian: East, Southeast, South
- American Indian or Alaska Native
- Native Hawaiian or other Pacific Islander (not Asian)
- Latino or Hispanic (20 countries)
- White: Europe, Middle East, N Africa





Health Disparity Populations

- -Health disparity populations include:
 - racial/ethnic minorities defined by OMB
 - •less privileged socio-economic status
 - underserved rural residents, and/or
 - sexual gender minorities
- -Populations have poorer health outcomes often attributed in part to social disadvantage, being subject to discrimination, and underserved in the full spectrum of health care.





Health Disparity Outcomes

- Higher incidence and/or prevalence
- Burden of disease measured by Disability-Adjusted Life Years (DALYS)
- Premature and/or excessive mortality in areas where populations differ
- Poorer health-related quality of life and/or daily functioning using standardized measures





Mechanisms Leading to Health Disparities



Individual Behaviors, Lifestyle, Beliefs and Response to chronic Stress: racism, childhood adverse conditions, food insecurity, witness to or victim of violence, immigrant, limited English proficiency



Biological Processes and Genetics: earlier age of onset, gene variants, metabolic differences, susceptibility, faster progression or greater severity, brain networks, microbiome, extracellular RNA



Physical and Cultural Environment: place, social system, neighborhood, infrastructure, family, social interactions, network, community cohesion



Clinical Events and Health Care: differential treatments, poor communication, adverse events to medications, falls, progression of disease, access, use/abuse of appropriate services, end of life care

Health Disparity Populations: Race/Ethnicity, Low SES, Rural, Sexual/Gender Minority Other Fundamental Characteristics: Sex/Gender, Disability, Geographic Region

Domains of Influence		Levels of Influence				
		Individual	Interpersonal	Community	Societal	
Biological		Biological Vulnerability and Mechanisms	Caregiver-Child Interaction Family Microbiome	Community Illness Exposure Herd Immunity	Sanitation Immunization Pathogen exposure	
Behavioral		Health Behaviors Coping Strategies	Family Functioning School/Work Functioning	Community Functioning	Policies and Laws	
Physical/ Built Environment	Lifeco	Personal Environment	Household Environment School/ Work Environment	Community Environment Community Resources	Societal Structure	
Sociocultural Environment	course	Sociodemographic Limited English Cultural Identity Response to Discrimination	Social Networks Family/Peer Norms Interpersonal Discrimination	Community Norms Local Structural Discrimination	Societal Norms Societal Structural Discrimination	
Healthcare System		Insurance Coverage Health Literacy Treatment Preferences	Patient-Clinician Relationship Medical Decision- Making	Availability of Health Services Safety Net Services	Quality of Care Healthcare Policies	
Health Outcomes		Individual Health	Family/ Organizational Health	Community Health	Population Health	



Inclusion of Diverse Participants

- All disparity populations are historically underrepresented in biomedical research
- Inclusion of minorities in clinical studies is an goal of NIMHD but separate from research
- Social justice, good science, and common sense mandate inclusion (40% US population)
- In 2014, 26% of participants in NIH-funded clinical studies were minorities; 11% Blacks







We Have to be at The Table

- Yes, it is harder to recruit minorities and it usually takes more resources and different skills
- More face time and personal messages
- Minority scientists are generally better at it
- We need greater granularity (SES, birthplace, language) and investigator accountability
- End myth that barriers are insurmountable





NIMHD's Language Access Portal

The Language Access Portal (LAP):

- Purpose: Improves access to cross-cultural and linguistically appropriate health information.
- Design: Consolidates health resources from across NIH and other federal agencies that are available in select languages for populations experiencing significant health disparities.
- Audience: NIMHD research community, public and community health professionals, clinicians, and others working with limited English proficient (LEP) populations
- Rationale: provide meaningful access to services and information for persons with LEP



Visit https://www.nimhd.nih.gov/programs/edutraining/language-access/



Diversity in Science and Medicine is a Demographic Mandate

- Develop a diverse clinical workforce that will care for our patients
- Medical school graduates in 2014: 5% Latino, 6% African American, <1% American Indian
- Develop a diverse biomedical scientific workforce that will conduct research in all areas of science
- About 7% of all NIH R01 grants are awarded to African American and Latino Pls; apparent bias in funding Blacks





Fostering the Next Generation of Researchers

2017 Health
Disparities
Research Institute

August 14 - 18, 2017







Musculoskeletal and Arthritis Disorders in Minority Health and Health Disparities

- Systemic Lupus: all minorities with increased risk and severity
- SLE and renal disease leads to worse outcomes in Blacks
- Scleroderma: Al/AN
- Osteoarthritis: More disability and quality of life impact on Blacks
- Rheumatoid Arthritis: African Am, Latinos, Asian, poor



Dermatological Clinical Issues in Minority Health and Health Disparities

- Chronic pruritus: 6000 Veterans surveyed about quality of life
- Non-Whites had more burning, scarring emotional impact, and primary care visits
- Atopic dermatitis: African Am
- Vitiligo: Dark skin persons



Arthritis-Attributable Activity Limitation National Health Interview Survey, 2013-2015

	% Sample	Prevalence
White	76.0	40.1
Black	11.2	48.6
Asian	2.7	37.6
American Indian/AN	0.6	51.6
Latino	8.1	44.3

Educational Level	% Sample	Prevalence
< High School	15.1	52.1
High School / GED	28.5	43.1
Some College / Tech	31.1	43.6
College Graduate	25.4	32.1

MMWR, March 10, 2017: 66: 246-2538



Policy Strategies to Reduce Health Care Disparities

- Expand Access: Health insurance, place and clinician as fundamental
- Public Health Consensus
- Coordination of Care: Systems, navigators, and target conditions
- Patient-Centered: PCMH, effective communication, cultural competence
- Performance measurement: Risk



Perception of Unfair Treatment: 2015

In past 30 days were you treated unfairly because of racial or ethnic background in store, work, entertainment place, dealing with police, or getting healthcare?	Percent agree
Latinos	36% / 14%
African Americans	53% / 12%
Whites	15% / 5%

Kaiser Family Foundation Survey of Americans on Race, November 2015.



Community Engaged Research to Reduce Health Disparities: What is Needed?

- Shift models of care to population health with accurate demographic and social determinants of health
- Enhance access to health care services: portal for patients, e-referrals, tele-medicine
- Address access to real food and safe places
- Engage community resources in promoting health: nutrition, physical space, tobacco
- Recognize and manage discrimination





Precision Medicine and Clinical Care

- When is "more precise" individualized approach better than a standard one with demonstrated efficacy?
- One size fits all approach can work to improve outcomes in many clinical situations
- New is not always better and is usually more expensive — cost has to be considered
- Precision in patient-clinician interactions
- Enhance cultural competence and reduce structural discrimination





NIMHD Intramural Program

- Population science emphasis with clinical component
- Recruited scientific director who will start in November
- Recruit new scientists including a clinician
- Propose cohort study
- Network with DIR programs with MH/HD interests: NCI, NIA, NIDDK, NICHD, NIEHS, NHLBI, NIAMS





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